



# Congressman Tim Bishop

*FIRST DISTRICT -- NEW YORK*

## **MEDIA RELEASE**

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**CONTACT: BRIAN FARBER**  
**PHONE: (202) 225-3826**

### **HAPPY BIRTHDAY! BISHOP OFFERS SPECIAL WISH TO GRACE PESHKUR ON HOUSE FLOOR**

*Congressman Brings National Focus to Holtsville 4-Year-Old Suffering from EB*

**WASHINGTON, DC** - Congressman Tim Bishop wished Grace Peshkur of Holtsville a very special 4<sup>th</sup> birthday on the floor of the U.S. House of Representatives this morning. Grace suffers from Epidermolysis Bullosa (EB), a rare skin disorder. In his statement, Bishop also asked Members to support his bill, House Resolution 335, which would reserve the last week of October as National Epidermolysis Bullosa Awareness Week. Bishop introduced the bill with Congressman Peter King, Chairman of the House Homeland Security Committee.

EB is a rare disease characterized by the presence of extremely fragile skin that results in the development of recurrent, painful blisters, open sores, and in some forms of the disease, in disfiguring scars, disabling musculoskeletal deformities, and internal blistering. Writing, eating, walking, and seams of clothing can trigger painful reactions and skin irritations making the lives of the family and children almost intolerable. The disease affects approximately 12,500 individuals in the United States. There is no cure for EB.

Grace Peshkur suffers from the worst possible form of EB (Recessive Dystrophic). Her condition is so rare that the medical community has difficulty treating it at times. Grace has blisters all over her body as well as internal problems. She has special bandages that must be wrapped around most of her body twice every day. The "dressing" changes require 4 adults and last anywhere from one to two hours. Because Grace needs constant care, Grace's mother is unable to work.

The community has been very active in supporting the Peshkurs, including fundraising to build a new home for Grace.

"I am proud of the way our community rallies together to help one another," Bishop said. "It is one of the things that make this area a great place to live."

The full transcript of Bishop's statement is located below. However, video of the floor statement is available at <http://www.house.gov/timbishop>.

**One Minute Statement**  
**Hon. Tim Bishop**  
**March 29, 2006**

Mr. Speaker, I rise to recognize Grace Peshkur and her family on the occasion of her fourth birthday today.

Grace is an extraordinary child, who has endured a life of struggle – and yet she has persevered – against a rare skin disease and genetic disorder called Epidermolysis Bullosa – or “EB” for short.

Grace is an inspiration to many long Island families who have rallied around her. She has helped raise awareness about EB, which I had never heard of before meeting Grace.

Over 12,000 Americans like Grace are afflicted with EB. The symptoms are fragile skin, recurrent blisters and painful sores caused by minor rubbing and that can be aggravated by routine activities we take for granted – like eating, walking, and even changing clothes.

For Grace and her family, every day that goes by is another battle won. I admire the Peshkur family and over 12,000 other Americans afflicted with EB who fight this disease and are working to raise awareness, find better treatments, and ultimately discover a cure.

In lieu of a 4<sup>th</sup> birthday present for Grace, I encourage my colleagues to cosponsor H. Res. 335, which would raise awareness by creating an EB awareness week.

Mr. Speaker, we can only imagine the difficulty that Grace and her family face on a daily basis, but we can do something about it. We can provide the hope and promise of a cure.

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